Quality of life in mental disorders: challenges for research and clinical practice

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The term quality of life (Qol) has become a rallying cry for all those who strive to integrate patients' subjective experience of their life during illness into clinical care. With its intuitive appeal, Qol seems to be understood by everyone involved in managing health and disease. However, when examining the ever increasing research literature, it becomes clear that many methodological questions still beset this field, since neither a commonly accepted definition nor a gold standard for measuring Qol exist. On the contrary, one is irritated by the myriad of different instruments and it remains questionable how valid and comparable research results obtained with different instruments are. It is argued that, especially when attempting to measure Qol in mental disorders: a) in addition to "subjective", also "objective" (i.e., external) assessment is needed; b) the inclusion of psychopathological symptoms in Qol instruments has to be controlled for; c) in addition to well-being and satisfaction, also functioning and environmental assets have to be assessed; d) different life areas have to be considered separately, and e) changes over time have to be taken into account. A concluding section in the paper reflects on the still largely missing transfer of research results into clinical care.

Key words: Quality of life, well-being, satisfaction, measurement, mental disorders

In the scientific medical literature, the term Qol is used with many different meanings and refers to an only loosely related body of work on psychological well-being, social and emotional functioning, functional performance, life satisfaction, social support, etc. It seems that all non-medical aspects of disease are subsumed under the umbrella term of Qol, without a generally accepted definition, and it is justified to conclude that Qol is a term describing a *field* of interest rather than corresponding to a *single variable* – much in analogy to the term "disease" – and that there is no simple way of measuring Qol, just as there is no simple way of measuring disease. Nevertheless, year by year, literally thousands of scientific medical publications are forthcoming purporting to measure a single entity called Qol.

The present article explores the tension between the common sense meaning of Qol and the attempts to pin it down to a measurable concept – with the laudable motive of adding the much needed human aspect to the ever increasing preponderance of technological aspects in medicine, thereby using the same scientific approach as biological clinical research, namely quantification, operationalization and clinical trials, commonly regarded as the evidence based approach to obtaining knowledge in the field of medicine (1).

This undertaking is still beset by numerous methodological pitfalls and biases which often make findings difficult to interpret and sometimes lead to wrong conclusions. After briefly describing the rise of the Qol concept in medicine, the main part of this article will therefore discuss these methodological challenges for Qol research in relation to mental health. Also, since the necessary link between quality of life research and medical practice is still weak – with a tendency of "l'art pour l'art" research dominating in academic environments, and marketing research in industrial ones – a concluding section will deal with new developments in the mental health field which may pave the way for integrating the Qol approach into clinical practice.

THE RISE OF THE QUALITY OF LIFE CONCEPT IN MEDICINE

The concept of Qol has its main roots outside the health care field, in the positive psychology movement (2) and in social indicator research of the 1960s and 1970s (3). In medicine, it started to be used indirectly in the 1980s in what has been called health status research, when, among others, instruments for assessing social functioning (such as the Short Form-36, SF-36) were developed (4).

The first documented use of the term in the medical literature dates 40 years back. In a 1966 article on transplantation medicine, Elkinton criticizes medicine as doing the "tuning with unprecedented skill" but having "trouble with the harmony", and goes on to ask: "What is the harmony within a man, and between a man and his world – the *quality of life* – to which the patient, the physician, and society aspire?" (5).

Over the following two to three decades, the numbers of medical publications on Qol rose only slowly. Since the early 1990s, in nearly all fields of medicine a tremendous increase can be observed. According to a Medline search, more than 7000 papers were published on Qol in 2004, a more than threefold increase over 1995.

As a way of stressing the psychosocial aspects of diseases, the Qol concept seems to have replaced the notion of the "biopsychosocial model of disease", proposed by Engel in 1977 (6) to counterbalance the deficiencies of the "reductionist" biomedical model. Today the "biopsychosocial model of disease" has not reached anything like such a wide acceptance in the medical literature as the Qol concept (7).

The medical specialty where the Qol concept gained first prominence was oncology, where, with the arrival of "aggressive" treatments, the question arose whether one should trade off a longer survival time (with unpleasant treatments) for a better quality of life (without treatment). "I'd rather die with my own hair on", says a character in David Lodge's novel "Paradise News", when asked why she refuses chemotherapy for cancer. In psychiatry, similar issues have been prevalent for a long time. The question whether "the cure is worse than the disease" arose, for instance, in asylum psychiatry (8), as well as in the treatment of schizophrenia with conventional neuroleptic drugs (9).

Angermeyer and Kilian have recently reviewed the Qol concepts used in the literature and have distinguished three models (10): a) the "subjective satisfaction model" (the level of Qol experienced by an individual depends on whether or not his/her actual living conditions meet his/her needs, wants, and wishes) (11); b) the "combined subjective satisfaction/importance model" (which gives different weights to different life domains) (12); and c) the "role functioning model" (the individual enjoys a good quality of life if he/she performs adequately and his/her needs are satisfied appropriately) (13). The authors go on to present their own "dynamic process model of Qol" with the interacting components of the environment, the person and cognitive adaptation processes (10).

Albrecht and Fitzpatrick (14) have identified four uses of the Qol concept in relation to medicine: a) as an outcome measure in clinical trials and health services research; b) for assessing the health needs of populations; c) for the planning of clinical care of individual patients, and d) for resource allocation. Of these, the first two relate to research, which will be discussed below.

RESEARCH AND MEASUREMENT

Today Qol measures are increasingly employed as an outcome variable in clinical drug trials, not the least because regulatory authorities are asking for this type of information (15-17). A similar use as outcome measure can be found in health services research (18,19). Moreover, studies describing Qol in various diagnostic groups, in clinical settings and in epidemiological surveys, are increasing in number and are usually carried out with the purpose of demonstrating how large the "burden" of a specific mental disorder is. A number of methodological assessment issues have still to be resolved, though, before definite conclusions can be reached in these areas.

The "subjective" vs. "objective" issue

In the health care field, the term Qol has become a rallying cry for all those who strive to integrate patients' subjective experience of their life during illness into clinical care, mainly by relying on patients' *subjective* assessment of their Qol (20,21). In somatic medicine, this is fully appropriate, since a subjective view of this kind had been neglected by medicine for a long time. Corresponding to this notion, most Qol assessment methods are either straight-

forward self-rating scales or, if applied as an interview, explicitly pick up the patient's point of view. This emphasis of today's medical Qol research on subjectivity and on individual persons' well-being and satisfaction with life (or specific life domains), as well as on the individual's perception of his/her daily functioning, is more related to the happiness than to the social indicator research tradition.

When dealing with mental disorders, this widely accepted position of concentrating on the subjective perspective of the patient is prone to measurement distortions. Reports about subjective well-being often tend to simply reflect altered psychological states, as Atkinson et al (22) and Katschnig et al (23) have shown for depression. In addition, subjective reports about functioning in social roles and about material and social living conditions may be distorted for several reasons, which can be called "psychopathological fallacies" and which cannot be easily corrected. These include the "affective fallacy", the "cognitive fallacy", and the "reality distortion fallacy".

The most relevant of these fallacies is the *affective* one, since it tends to be overlooked and might lead to wrong conclusions (23). It has been shown that people use their momentary affective state as information in making judgements of how happy and satisfied they are with their lives in general (24). A depressed patient will usually see his/her well-being, social functioning, and living conditions as worse than they appear to an independent observer (25,26) or to himself/herself after recovery (27). The opposite is true for a manic patient who, quite naturally, rates his/her subjective well-being as excellent, but also evaluates social functioning and environmental living conditions as unduly favourable.

Mechanic et al (28) have shown that depressed mood (in addition to perceived stigma) is a powerful determinant of a negative evaluation of subjective Qol in patients suffering from schizophrenia (29). Both in research and clinical practice, the affective fallacy can lead to wrong conclusions. For instance, in general medicine, Qol measures might disguise the presence of a comorbid depression which, as a consequence, might not be discovered and therefore not treated (30). In research on the effectiveness of antidepressant drugs, the very improvement of symptoms implies that the patient views the self, the world, and the future more positively (25); this will automatically show up in a Qol instrument measuring subjective well-being and satisfaction with life, leading investigators to conclude that a specific drug does not only improve symptoms but also Qol - which in some sense is true, but is basically a tautological statement.

The *reality distortion* and *cognitive* fallacies are less problematic, since they are more readily recognized. At times, patients suffer from delusions and hallucinations, which distort their perception of themselves and their surrounding. Taking a deluded or hallucinating patient's judgement on his/her quality of life as granted would constitute the *reality distortion fallacy*. The *cognitive fallacy* concerns wrong evaluations by patients who are unable to

assess intellectually their life situation, as is the case, for instance, in dementia and mental retardation.

Thus, while the patient's own view seems to be necessary, the question arises whether the subjective view is sufficient to assess Ool in persons suffering from a mental disorder. Becker et al (12,31) contend that, in the field of psychiatry, Qol assessment has to be carried out not only via the patient, but also via professional helpers and key informants, as a rule family members and friends. Accordingly, in addition to a patient version, the authors provide also a "professional" and a "carer" version of their Wisconsin Quality of Life Index (W-QLI). There is empirical evidence for this position: Sainfort et al (32) have demonstrated that such assessments differ between patients and their relatives. It has also been shown that persons suffering from schizophrenia, when moved from a mental hospital to the community, showed no improvements in life satisfaction ratings, despite "objectively" improved living conditions and increased leisure activities (33,34).

These observations warrant the conclusion that additional evaluations by professionals and by family members and friends are necessary to complement the patient's own subjective assessment. However, assessment by other persons is not *per se* objective, and the term "objective" may be misleading. "External assessment" is probably more appropriate than "objective assessment", since such an evaluation might reflect the subjective view of the assessors themselves.

This Qol assessment issue brings into the forefront a basic problem of psychiatry – the necessity to reflect the different viewpoints which exist in society, e.g. about whether a psychiatric disorder is present or not and whether something should be done about it or not. Most often, there is disagreement on this matter between the patient, his family, professionals, and the society at large, and such disagreement should at least be documented (35). In practice, however, even if one acknowledges the necessity to include the "external" perspective, this cannot be easily achieved, if the relevant resources are not available.

Psychopathological symptoms and measures of well-being: a case of measurement redundancy

The above issue becomes even more salient in the light of the next problem. Most Qol instruments used in medical patients contain "emotional" items, mostly relating to the field of depression and anxiety. Some authors even speak of an "emotional-function domain" or of a "pleasant affect" versus "unpleasant affect" component (2). Here, the psychological tradition of measuring quality of life by "well-being measures" becomes tautological, since, if the item content of both measures is largely overlapping, Qol measures are necessarily correlated with measures of psychopathology.

The use of Qol as an outcome measure in clinical trials and evaluative studies has increased over recent years, but

– given the lack of a clear-cut definition and the very broad concept of Qol – there is a danger that therapeutic strategies are promoted on the basis of ill-demonstrated benefits for Qol itself. One example is the Quality of Life Scale (QLS) (36), which has often been applied in clinical trials of the atypical antipsychotics to show improvement in Qol. An analysis of the item content of the QLS shows that it mainly describes negative symptoms. Another example is the Quality of Life in Depression Scale (QLDS) (37), which is made up mainly of depressive symptoms (23). A cautionary stance should therefore be taken by regulatory bodies (which increasingly demand that a new drug is not only improving symptoms but also Qol) that it is not just a new label (Ool) which is glued on an old bottle (symptoms).

If Qol is studied in the mental health field, it is strongly recommended to always control for the presence of psychopathological items in Qol instruments used for a specific study, i.e. to check the correlations found between Qol measures and psychopathological symptoms for possible spuriousness because of simple item overlap. Also, when studying Qol in somatic disorders, at least depressive and anxiety symptoms should be assessed, in order to evaluate their possible impact on the Qol measures. This is especially important in view of the high comorbidity of somatic with mental disorders, especially if the former are chronic (30).

Beyond well-being: functioning and environmental assets

If Qol is to be assessed in persons suffering from mental disorders, the exclusion of contextual factors from many Qol measures is an even greater problem.

Calman (38) has elegantly defined quality of life as "the gap between a person's expectations and achievements". This gap can be kept small in two ways: living up to one's expectations or lowering these expectations. Lowering one's expectations is an adaptational psychological process. Happiness research has shown that most people are happy and that, by and large, this does not depend a great deal on environmental factors (2). Obviously, a large gap between expectations and achievements is not easily bearable, and most people lower their expectations (or don't have too high expectations to start with). Otherwise, the finding that people living in Detroit and Madras, the rich and the poor, the young and the old, are on average equally happy, could not be explained.

It has also been noted that many persons suffering from long-term mental disorders report themselves satisfied with life conditions which would be regarded as inadequate by external standards. It seems that these persons lower their standards over time and thus keep the gap between expectations and achievements narrow: if one cannot possibly achieve one's aims, these aims are changed, a phenomenon which could be called "standard drift fallacy".

Nevertheless, it is true that "achievements" do not

depend only on subjective factors, but also on the actual opportunities available in one's environment. If Qol assessment is to lead to specific actions, then the inclusion of environmental factors seems necessary. It is contended here that Qol, understood in this way, has to be differentiated at least according to three components: psychological well-being/satisfaction, functioning in social roles, and contextual factors (both social and material).

The need to include contextual factors into the assessment of Qol is especially pressing in the case of persons suffering from mental disorders, where such factors interact with the patient's disorder more than in somatic disorders. Income, social support, and living conditions (also called "standard of living") can be intimately related to psychopathology (39).

The needs assessment approach in social psychiatry brings in the environment (40,41). Also, community psychiatry as such is including the environment into its spectrum of helping activities. Working with family members, providing a day structure, offering jobs, are only a few such examples. Katschnig et al (23) have developed an actionorientated framework for assessing quality of life in depressed patients, which includes the aforementioned three components of well-being/satisfaction, functioning in social roles and contextual factors. They give examples of how helping activities could be classified according to these components: some act on psychological well-being (e.g., antidepressants), some on role functioning (e.g., social skills training), and some on environmental circumstances (e.g., providing money or housing). Also, public health programmes aiming at the promotion of mental health and improvement of the Qol of whole populations do in fact take all these factors into consideration (42).

Qol profile vs. global Qol measures

Keeping patients with persisting mental disorders in mental hospitals might have had the advantage of fulfilling the most basic human needs (physiological such as food and security such as shelter), but higher human needs (like that for autonomy) were neglected in these settings (43). On the other hand, in the era of community psychiatry, patients with persisting mental disorders do have the possibility of gaining autonomy, but often at the possible expense of not getting their basic human needs fulfilled.

Psychiatric patients have the specific problem of being stigmatized when they declare themselves as being mentally ill, which seems necessary if they want to obtain the means for survival, including their additional needs for treatment (drugs, social security benefits, etc.). Such stigma jeopardises autonomy, since patients are excluded from society, while they want to be "one of us", as qualitative research shows (44). Many psychiatric patients are thus in a no-win situation as far as the fulfilment of their needs is concerned, and many give up some of their expectations

and "cut their coat to their cloth" (45).

In addition to having specific additional needs for treatment, psychiatric patients are disadvantaged since they usually have fewer resources to cope with life problems, fewer social and cognitive skills, and fewer environmental assets, especially money. In many studies on the quality of life of patients with schizophrenia in the community, lack of money is a prominent complaint, probably because it stands for autonomy.

From this discussion it becomes clear that single Qol measures are not appropriate, given the many different needs and the different importance attached to different life domains by different patients (12). A Qol profile is more appropriate (46). For planning interventions and assessing outcome in a single patient and in clinical trials, a structured multi-dimensional use of the Ool concept is necessary, which covers different specific life domains, such as work, family life, money, etc. Some psychiatric Qol instruments separate such domains from each other - e.g., the Ouality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) (47) and the W-QLI (12) – while others do not. For economic evaluation, a single index might be convenient, but this approach simplifies matters to such a degree that it becomes more difficult to understand what the figure obtained actually means (48).

Instruments for assessing patients' needs are in fact multi-dimensional, like the Needs for Care Assessment instrument of the Medical Research Council Unit in London (MRC-NCA) (40) and the Camberwell Assessment of Need (CAN) (41), implying that different actions are necessary for different needs in different life areas. A specific Management Orientated Needs Assessment instrument (MONA) following these lines has actually been developed by Amering et al (49) in Vienna. This instrument also covers the possibility that the patient regards some life areas as more important than others in terms of actions to be taken.

Qol and time

Health related Qol assessments usually refer to a specific point in time or time period. However, there are quite a few time aspects involved when making such assessments.

First, the question arises whether the meaning of Qol remains the same in an individual person over time. As has been shown by Bernhard et al (50), the meaning of Qol does not remain constant over time in patients who undergo treatment for severe diseases. In particular, the weight given to Qol domains changes over distinct clinical phases. Also, Morgado et al (27) found that, after remission, depressed patients re-assess their social adjustment as having been wrongly evaluated too negatively while they were still in their depressive episode.

Secondly, each of the three different components of quality of life – subjective well-being and satisfaction with different life aspects, objective functioning in social roles,

and environmental living conditions (standard of living, social support) - has different time implications. Subjective well-being, which is largely dependent on the actual affective state, can fluctuate quickly. Functioning in social roles may break down rather quickly, though it more often takes some time. Environmental living conditions - both material and social - change only slowly in most cases. Thus, a depressed patient whose subjective well-being declines quickly while depression is worsening, may still go on to function in his/her social roles. Even if this person does break down in functioning, the material living conditions and social support might still be unchanged for some time. On the other hand, once social functioning has deteriorated due to the long duration of the disease, while environmental assets, both material and social, have diminished, a patient might recover quickly in his psychological well-being, but not in social roles functioning. Also, it might take some time before environmental living conditions are re-established, if they are at all.

Thus, if Qol is equated with "subjective well-being", then "changes in quality of life" might be observed after short psychopharmacological intervention. However, if functioning in social roles is being considered, the chances are less clear-cut that drugs might lead to quick improvement. Finally, if social support and material living conditions are to improve again, it will probably take much longer and need other than psychopharmacological interventions.

A third, more complex time issue can best be characterized by the "gap" between a person's expectations and achievements described by Calman (38). If this gap is small, Qol is high. In this perspective, for each person, the issue arises of what is more important to him/her: a good quality of life today or one tomorrow, i.e. keeping the gap narrow now or tomorrow? There are numerous ways for persons suffering from mental disorders of achieving a short-term harmony between expectations and achievements, the use of quickly acting psychotropic substances (such as tranquilizers or alcohol) being the most common of these. In the long term, of course, substance abuse might develop and lead to a widening of this gap, following a vicious circle which implies decreased psychological well-being, loss of functioning in social roles, and deteriorating environmental and social living conditions. In the era of the predominant use of the first generation neuroleptics, patients experienced exactly this dilemma: while the prophylactic use of neuroleptics decreased the frequency of relapses, the side effects were often so disturbing that many patients were in the dilemma of having to choose between sustaining the side-effects "now" (i.e., the immediate "costs") and then have a good quality of life "tomorrow" (i.e., the future benefits), or not experiencing side effects "today", and having an increased risk of relapse "tomorrow". It seems that quite a few patients preferred the "better quality of life now" versus the "better quality of life tomorrow" (9). The new atypical antipsychotics might change this situation.

FROM ASSESSMENT TO ACTION

Today, in clinical trials and health services research, Qol measures are often included in order to *describe effects* of treatments or of special ways of delivering these treatments; but, as a rule, they are not themselves a *target of intervention*. In this respect some new developments are under way which may have long reaching consequences for the whole health field, including not only treatment and rehabilitation, but also prevention, and finally also promotion of health.

The use of Qol instruments in everyday clinical practice to improve clinicians' awareness of patients' disabilities and general well-being, while having been judged as uncommon in the early 1990s (51), seems to gain ground now. One reason for this development is the advent of computer assisted monitoring in clinical practice (52-54). Needs assessment instruments for patients suffering from mental disorders, such as the MRC-NCA or the CAN, might thus find their way into clinical routine (40,41).

Other developments can be observed which might contribute to supplementing the traditional disease-oriented clinical paradigm not only in research but also in daily practice by a Qol approach. For instance, Frisch (55) coined the concept of "quality of life therapy", which he links to specific assessments by his structured Quality of Life Inventory (QOLI), i.e. the Qol assessment is taken as a basis for specific Qol interventions, meaning interventions that focus on enhancing Qol – in a similar way as a psychiatrist elicits psychopathological symptoms, makes a diagnosis and then decides which specific psychiatric treatments to be used. The difference in Frisch's approach (which he exemplifies for the case of depression) is his focus of action on Qol instead of symptoms (56).

Another new development in clinical settings which focuses on interventions on non-disease aspects is so-called "motivational interviewing" (MI) (57). MI aims at changing life styles of patients and is used mainly in the substance abuse field, but increasingly also in other health fields (58).

While in MI the term Qol is not directly used, one could nevertheless say that this technique aims at improving Qol. The same holds true for some ongoing activities in the mental health care field. The so-called recovery movement de facto also puts emphasis on Qol interventions, without calling them as such (59,60). In Vienna we have developed management tools and services for improving Qol in persons suffering from mental disorders including their families. A new psycho-educational tool for use in schizophrenia focuses as much on Qol issues as on disease aspects (61), and a family-orientated residential facility ("Pension Bettina") functions as a "school for living with schizophrenia" (62). These and similar programmes - e.g., patients, caregivers and professionals discuss, outside the traditional familial therapeutic and institutional context, the experiences and consequences of psychosis and ways to cope ("trialogue") - emphasize empowerment, advocacy, and self-help (63). This philosophy is in line with the principles of "promotion of mental health", which can also be regarded as a means of improving quality of life in whole populations – in healthy persons, in those at risk for, and in those already suffering from a mental disorder (42).

Obviously, activities are going on and still developing in the field of mental health care, which regard Qol as equally important as disease aspects. The request of Qol data by regulatory authorities for new pharmacological treatments to be admitted to the market is also a sign of increasing awareness of Qol needs of persons suffering from mental disorders.

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